INITIAL VERSION OF DCE QUESTIONNAIRE

The NEXT Medicine Patient Preference Questionnaire

Thank you for your participation in the NEXT Medicine study and in your interest in completing this questionnaire. The goal of this questionnaire is to learn what types of genetic tests patients feel are worthwhile and informative as part of their clinical care.

We would like you to evaluate how you value different genetic tests by answering several questions. Each question describes 3 possible genetic testing scenarios. For each question, we ask you to pick the genetic test you think is the best choice. We are gathering information on what you think is important and what your preferences are. We are interested in your option. However, your answers will have no affect on the genetic tests you are offered as a part of the NEXT medicine study or your clinical care now

Your participation is voluntary. You are under no obligation to participate in this questionnaire. If you decide to participate, you can skip any question or stop at any time without any consequence. The survey will take about 30 minutes to complete. We will not share your identified responses with anybody else. The information you provide is strictly confidential.

BACKGROUND INFORMATION

Please Read Carefully. The following description will help you understand and complete the rest of the questionnaire.

Some of the benefits of finding a genetic cause of colorectal cancer may include:

- Knowing if the cause of colorectal cancer disease is inherited (genetic) or sporadic (random or environmental)
- Better treatment options
- Information regarding family members' risk of developing colorectal cancer
- Access for families to early cancer screening programs

Unfortunately, even the best genetic tests available cannot identify all genetic causes. But some newer technology tests may be able to identify more genetic causes than others. These newer genetic tests can also provide information about risk for other diseases not related to a current disease. Test results regarding risk for other diseases are called 'incidental findings,' because they were obtained incidentally (or extra) to the primary test result for colorectal cancer.

There is a trade-off involved in receiving such new technology test results that may provide more accurate tests that provide a better chance of diagnoses, or offer information on incidental findings.

Some of the possible side consequences of getting information with the new genetic testing is that they may:

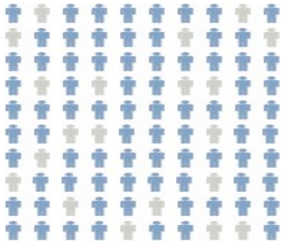
- Cost more
- Be more complicated to understand because there is additional information not related to the current disease
- Cause undue worry, especially if an incidental finding provides information about a disease that someone had no idea they were at risk for.

The following pages describe five characteristics of the genetic tests. These are the characteristics we want you to consider when making a decision about what test you prefer most. **Please only consider the characteristics presented.**

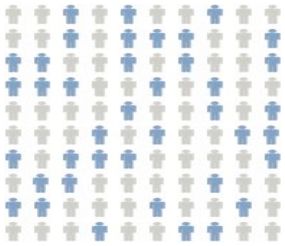
CHARACTERISTICS OF THE TEST

The scenarios you will choose between differ according to following five characteristics:

1. **Number of individuals that receive a genetic diagnosis related to their current disease:**
    - For example, for every 100 people who undergo testing, a test will identify 80 people who have a genetic cause of their colorectal cancer/ polyposis syndrome. The diagram below shows 80 people (blue) who receive a genetic diagnosis related to their disease.



    - Another test may provide a diagnosis in 40 people for every 100 who are tested. The diagram below shows 40 people (blue) who receive a genetic diagnosis related to their disease.



2. **Treatability of disease identified by one or more 'incidental findings' – a disease unrelated to your current disease:**
    - For example, the genetic test can provide you with additional information on your risk for having other diseases that are readily treatable or preventable by medicine or preventative measures.

    - A genetic test may also provide you information on your risk for diseases that have moderate or severe health consequences but are not treatable or preventable
        - ***Moderate health consequences can include***: some problems with short-term memory, some problems caring for yourself, some problems walking, some problems with communicating, and/or a slight decrease in life expectancy.

        - ***Severe long-term health consequences can include***: significant problems with long-term and short-term memory, unable to independently care for yourself, unable to walk, problems with communicating, and/or a large decrease life in life expectancy.

CHARACTERISTICS OF THE TEST *(continued)*

3. **Family impact of disease identified by one or more 'incidental findings' – a disease unrelated to your current disease:**
    - Risk of passing on to children genetically-linked diseases that can be treated or prevented allowing for normal child development.

        Note: The genetically-linked disease may never cause disease in your child, but it may cause disease in future generations of your family

    - Risk of passing on to children genetically-linked diseases that can be treated or prevented but child will be limited by disease
        - These limitations include moderate and severe health consequences as was defined in characteristic 2 above.

    - Risk of passing on to children genetically linked diseases that have no treatments and cause moderate or severe health consequences

4. **Total time waiting for the results of the test or sequence of tests**
    - For example, it may take 3 **weeks** to receive the results of all genetic testing

    - For another genetic test, it may take 3 **months** to receive the results of the genetic tests

5. **Total cost to you of genetic testing**
    - For example, the total cost that you will need to pay out of pocket to have all genetic testing is **$750**

    - Genetic testing with other genetic testing may cost you **$3,000** out of pocket

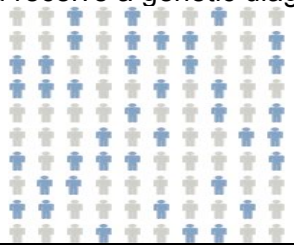
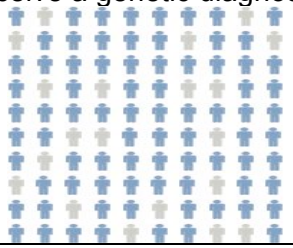
A Word of Caution.
Please Read!

Studies similar to this one show that people [often] overstate how much they are willing to pay for a genetic test. When this happens, the value of the genetic tests cannot be measured accurately.

When completing the following questions we ask that you carefully consider the cost characteristic and respond as if you would have to pay for the genetic test.

Below is an example of the type of question we will ask you in the survey:

Which type of genetic testing would you prefer? You must choose either Genetic Test A, Test B, or to have no genetic testing. The person who answered the question below decided that Genetic Test B was better than Genetic Test A and No Genetic Testing. They made this decision by first reading the descriptions of each genetic test separately and then compared Genetic Test A with Genetic Test B, or No Genetic Testing. They thought about the real-life consequences of each of the characteristics below.

Test characteristic	**Genetic Test A**	**Genetic Test B**	**No Genetic Testing**
Number of individuals that receive a genetic diagnosis related to their current disease	40 individuals out of 100 who are tested receive a genetic diagnosis 	80 individuals out of 100 who are tested receive a genetic diagnosis 	You will not receive a genetic test, nor a conclusive genetic diagnosis
Type of 'incidental findings'	Your risk for diseases that are readily treatable	Your risk for treatable diseases AND your risk for diseases with moderate health consequences but are not treatable	Information on your risk of genetically-linked diseases is provided to you based only on your family history
Family impact of 'incidental findings'	Risk of passing on to children diseases that have effective treatments allowing normal child development	Risk of passing on diseases that can be treated but child will be limited by the disease	No information
Time waiting for results of the test	3 weeks	4 months	Not relevant
The total cost to you	$4,000	$1,500	$ 0
Which genetic test do you prefer?	**Genetic Test A ☐**	**Genetic Test B ☑**	**Neither test ☐**

FINAL VERSION DCE QUESTIONNAIRE

VALUE OF GENETIC TESTING

We would like you to rate the value of different genetic tests that provide different information by answering several questions. For each question, we will ask you to choose the information you would prefer to receive as part of the genetic testing process. Your answers will have no effect on the genetic tests you are offered or your clinical care.

BACKGROUND INFORMATION

Please Read Carefully. The following description will help you complete the rest of the questionnaire.

New genetic tests can provide you with information about other diseases not related to your current disease. These types of results are called ***'incidental findings.'*** The extra information is 'incidental' because it would be found while conducting a test to look for a genetic cause of colorectal cancer.

The TRADE-OFFS involved in receiving information on other diseases *may* include***:***

- Genetic testing for incidental findings may not be covered by insurance. You may have to pay money for such genetic testing.
- Genetic testing for incidental findings may be complicated to understand because you receive additional information about a disease (or diseases) you have not thought about.
- Genetic testing for incidental findings may cause you worry, especially if an incidental finding provides information about a disease that will make you ill but cannot be prevented or treated.

The following pages provide a description of the characteristics of incidental findings. These are the characteristics to consider when making a decision about what test you prefer most. **Please consider only these characteristics when making your choices.**

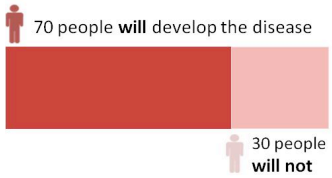
TYPE OF INFORMATION YOU CAN RECEIVE

The options you will choose between differ according to the following characteristics:

1. **Disease risk**

An incidental finding can provide you with information about your future risk of developing a disease over your lifetime. For example, the term '70% lifetime risk' means that for every 100 people with a 70% lifetime risk, 70 people will develop the disease over their lifetime.

For every 100 people with a
70% lifetime risk



Incidental findings about future disease risk could be provided at various thresholds for lifetime risk.

For example: ***A lifetime risk threshold of 90% or higher might return information about only one disease. By reducing the lifetime risk threshold to 70% or higher, it is likely that information about additional diseases will be provided, although the additional diseases will be of lower lifetime risk.***

Question for you to think about: For what level of lifetime risk would you want to receive incidental findings?

2. **Disease treatability**

Information about disease risk could be provided depending on whether there were effective, recommended treatments or lifestyle changes.

- For example, there currently exists a recommended and effective medical treatment for the disease.
- Or… there currently exists a recommended and effective lifestyle change, but no recommended effective medical treatment is available.

Question for you to think about: Would you want information about disease risk only for diseases that had an effective treatment or lifestyle change? Would you want information about disease risk *if there was no treatment*?

CHARACTERISTICS OF THE TEST *(continued)*

3. Disease severity

- The incidentally identified disease could have at least one the following effects on your health when you develop the disease, even if treatment is available. You could develop the effects of the diseases fairly soon, or years in the future.

    - ***Mild health consequences can include***: some or no problems with long-term or short-term memory, some or no problems caring for yourself, some or no problems walking, or some or no problems with communicating.

    - ***Moderate health consequences can include***: some problems with long-term or short-term memory, some problems caring for yourself, some problems walking, or some problems with communicating.

    - ***Severe health consequences can include***: significant problems with long-term and short-term memory, unable to independently care for yourself, unable to walk, or problems with communicating

4. Carrier Status: Information on your carrier status for a gene not affecting you, but could affect a family member

In some situations the genetic test will find a gene that does not indicate you are at risk for a disease, but it may have implications for your children, your grand children, or your brothers or sisters.

This situation arises because you can be a carrier for something called a recessive genomic change, or 'variant'. If you have a recessive genomic variant your brothers or sisters may also have the variant. Or you may have passed the recessive variant to your children. These genes may put an unborn baby at risk for a disease if both parents of the baby have the recessive genomic variant.

CHARACTERISTICS OF THE TEST *(continued)*

5. Drug Response: Information on your response to medications you may or may not be currently taking

- You receive a list of medications that are very likely to be more effective or have reduced treatment side effects.
    - Very likely means that the chance these medications are more effective or have reduced side effects is between **80% and 100%**
- Or you receive a list of medications that are moderately likely to be more effective or reduced treatment side effects
    - Moderately likely means that the chance these medications provide benefit to you is between **60% and 80%**

Note: information on medications may or may not be useful to you because you may or may not need to take these medications in the future.

6. Cost: Total cost to you of genetic testing

- For example, the total cost that you will need to pay **out of pocket** to have all genetic testing is **$750**
- Genetic testing with another test or sequence of tests may cost you a total of **$2,550 out of pocket**

NOTE: the genetic tests described in this survey are identical in their ability to provide you a genetic diagnosis for CRC.

Accurately valuing genetic tests

Please Read.

Before you tell us which genetic tests you prefer, we want to ask you to help us with a problem we have in studies like this one.

Because this survey doesn't require people to actually pay for the test, some people do not carefully consider the cost of the genetic test. It may seem easier just to notice that one cost is larger than another cost.

For example, suppose the cost levels are $100, $200, $500, and $750. People think of them as "very low", "low", "medium", and "high". They don't really think about what they would have to give up out of their monthly budget – such as restaurant meals or new clothing – to pay for the test.

Please help us value the genetic test accurately by paying attention to the actual costs of the test to you before deciding which of the alternatives you prefer.

The following page presents an EXAMPLE question.

THIS IS AN EXMAPLE QUESTION ONLY. Which test do you prefer? You must choose either Option A, Option B, or to have no information. The person who answered the question below decided that Option B was better than Option A and No information. They made this decision by comparing the characteristics of Option A with Option B and No information. They stated they were certain of the choice they made. It is ok to be uncertain about your choice.

	Option A	**Option B**	**No information**
Disease Risk You receive information on diseases that have the following lifetime risk or higher. *Note that more diseases will be identified if the lifetime risk is lower.*	Diseases with a **40% lifetime risk or higher**	Diseases with a **70% lifetime risk or higher**	No information
Disease Treatability Treatability of the newly identified disease(s)	No effective medical treatment or lifestyle change recommended	Recommended effective medical treatment only	Not relevant
Disease Severity Health consequences of the newly identified disease(s)	Mild health consequences	Severe health consequences	Not relevant
Carrier Status Carrier status for a gene not affecting you, but that may affect family members health	Information about whether your family members could be affected	Does not provide information on carrier status	No information
Drug Response Information on your likely response to medications you may or may not be currently taking	List of medications that are highly likely to be more effective or cause side effects	List of medications that are moderately likely to be more effective or cause side effects	No information
Cost to you not covered by insurance	$1000	$250	$ 0
Which test would you prefer? ***(Check one box)***	**Genetic Test A ☐**	**Genetic Test B ☑**	**Neither Test ☐**

How certain are you of your choice?